

2019-20 Annual Report



Canolfan
PRIME Cymru
Wales PRIME
Centre

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Foreword

PRIME Centre Wales aims to **improve health and well-being in Wales** and beyond through undertaking **high-quality research on topics of national policy priority**, which contribute to the **evidence base in primary and emergency care**, and ensuring that findings are **translated into policy and practice**.

Primary and emergency care sectors provide **90%** of all patient contacts within the NHS.

Changes in primary care will affect emergency and unscheduled care, and vice versa, and any changes in these sectors can ***critically affect the secondary and social care sectors***.

Worldwide evidence shows that **the stronger the primary and emergency care sector in that country, the stronger and more effective its whole health system is**. These sectors must be supported by a strong academic and research evidence base.

This is a vitally important area for research, engagement, knowledge mobilisation and impact, and PRIME is delivering this effectively and with an upwards trajectory, **with £49 million total over five years, including £25 million directly into Wales**.

Our research **aligns with Welsh Government Health and Social Care policies, plans and strategies**, including 'A Healthier Wales: our Plan for Health and Social Care' and 'Prosperity for All: the national

strategy' to ensure the delivery of health and care services that are fit for the future.

Together with our key stakeholders, we conduct research into:

- **prevention** as well as treatments,
- **improving** the standard and quality of treatments through generation of evidence,
- **integration** of health and social care,
- shifting health and care services **into communities** away from hospitals, and
- using **NHS and social care data** to better understand outcomes and prevention.

PRIME is an **all-Wales Centre** co-led by Cardiff University, Bangor University, University of South Wales and Swansea University.

The Wales Centre for Primary and Emergency care Research (PRIME Centre Wales) is funded by the Welsh Government through Health and Care Research Wales.

During 2019-20, PRIME has been awarded 20 new studies with a total grant value of over £9 million, including £5 million into Wales.

Across the five-year grant period (to March 2020), we have submitted 360 grant applications and 152 of these have been awarded (with multiple pending), totalling over £49 million, including £25 million into Wales.

Our application success rate over 5 years of 43% has been consistently above the national average for grants in applied health research.

Aims

PRIME aims to improve the health and well-being of the people in Wales by conducting high-quality research on topics of national policy priority in primary and emergency care and ensuring that findings are translated into policy and practice.

Our work involves:

1



Achieving **demonstrable research impact** by developing our research with our stakeholders, communicating research findings, working with stakeholders to ensure findings are implemented, and tracking evidence of impact.

2



Increasing the quantity of large scale, **high-quality research carried out in or led from Wales** through close collaboration with all our stakeholders, and attracting prestige research funding into Wales.

3



Undertaking research and dissemination activities that are **important to patients and the public** by involving service users, carers and the wider public in the prioritisation, design, conduct, interpretation and dissemination of research.

PRIME Centre Wales year in images, from top left to right:

Carolyn Wallace, PRIME work package lead, is appointed to Professor of Community Health and Care Services at University of South Wales;

Dr Ashra Khanom, PRIME Research Fellow at Swansea University, and her team of researchers from asylum-seeking and refugee communities won the **2019 Public Involvement Achievement Award** for their ground-breaking work on the HEAR study;

The **WICKED** research team, based at Bangor University, won the prize for the **best scientific poster** at the 2019 CRUK Early Diagnosis Conference for their poster 'Development of a primary care behaviour change intervention to expedite the diagnosis of symptomatic cancer in Wales a multi-dimensional approach'.

Joyce Kenkre, John Wynn-Jones and colleagues at the **WONCA 16th WONCA World Rural Health Conference** in Albuquerque, New Mexico (USA);

HEAR study team awarded the 2019 **Swansea University Medical School award** for outstanding contribution to outreach and public engagement.

PRIME Annual Meeting, November 2019, bottom row, left to right:

We were honoured to welcome guest speaker **Idris Baker**, Welsh National Clinical Lead for palliative and end of life care, and Consultant in Palliative Medicine who presented a Welsh Government and End of Life Board perspective of palliative and supportive care research in Wales.

SUPER group members at the poster viewing session;

Alison Porter, Associate Professor in Health Services Research and PRIME work package lead introduces the speakers.



April 2015 - March 2020

Summary of activities

Increasing the quantity of large scale, high-quality research

360 research grant applications submitted, 152 awarded, and 26 pending



Income generation

£49 million total generated in PRIME led & supported research funding, with £25 million into Wales



Increasing the evidence base

456 publications in primary and emergency care research, increasing the evidence base for policy & practice



Increasing capacity

116.9 full time equivalent posts created through funded research projects



Involving public and patients

546 public involvement opportunities created



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Lay summary

PRIME Centre Wales is a research centre which **brings together researchers, clinicians, patients, health service staff and other experts.**

We carry out **research about services and treatments provided in primary and emergency care settings** so we can improve health and wellbeing in Wales and beyond.

Nine out of ten patient contacts with the NHS happen in primary or emergency care settings. Changes in primary care will affect emergency and unplanned care and vice versa.

They will also affect secondary and social care sectors. So **effective primary and emergency care helps the whole NHS** and helps patients stay healthy for longer.

Four universities co-lead PRIME – Cardiff University, Swansea University, Bangor University and the University of South Wales. **We work together to pool our expertise.** We are funded by Health and Care Research Wales.

We **coordinate a group of public and patient members called SUPER** (Service Users for Primary and Emergency care Research) who meet with researchers to discuss research and also contribute to overseeing and delivering PRIME activity.

Our research teams also **involve people who commission, plan and deliver health services.** In this way, all perspectives and knowledge are in the team. We hold an annual meeting to tell people about our research.

During 2019-20, we have won 13 new studies with a total grant value of over £5.6 million including £1.9 million into Wales. We have published 91 peer reviewed articles including some of the results of studies we have recently completed.

Some of our key work and research findings of the last year include:

The **Social Prescribing Learning Needs Framework for practitioners in Wales** was developed by Carolyn Wallace and colleagues to inform the commissioning and decommissioning of training

for people delivering social prescribing in Wales.

We found that **adolescents living with long-term conditions** often feel as though they are left out of discussions and decisions with healthcare professionals, which can give them the impression that their views are not important. The team highlighted a number of ways that patients like are made to feel more involved, empowered and engaged to make decisions about their treatment using shared decision making.

We asked the general public in 8 countries what they thought about getting involved in research during a pandemic, and found that most people would value the opportunity to be involved, and this can be supported through the use of tailored information and specially designed initiatives to advance peoples' understanding of research and maintain trust in those leading the research.

We looked at the **impact of varying the duration of antibiotic treatment in older men with suspected urinary tract infection** and found that it's possible to safely reduce the number of days which patients take antibiotics from 7 to 3 days. We asked GPs to use a finger-prick point of care test in their surgeries to help inform their decision on whether antibiotics were needed to treat flare-ups in COPD patients, and found that it resulted in 20% fewer people needing antibiotics, with no negative effects on patients' recovery time.

We investigated why **people at high-risk for lung cancer** - current and former smokers aged over 40, may be reluctant to go to the doctor to get to seek help when they experience for lung cancer symptoms. We found that community based interventions have the potential to empower disadvantaged populations to seek help sooner.

We looked at the **needs of people who frequently call the emergency ambulance service** and found that many often have complex needs. Using multi-disciplinary case management approaches may help provide appropriate care, and reduce demand on emergency services.

We looked at **why patients are more likely to get**

wrongly diagnosed when they visit the hospital emergency departments using an analysis of national patient safety incident reporting. We found that there are multiple opportunities to reduce diagnostic error in the emergency department. Clinicians must have better support in performing patient assessment and interpreting investigations.

For the **prevention of tooth decay in children**, we found that applying fluoride varnish to children's teeth is just as effective at preventing tooth decay as the alternative method of sealing teeth. This could save the NHS money, and can be administered in a more convenient setting like schools via mobile dental clinics.

"This study provides invaluable evidence for National Health service dental services in the UK and has implications for dental prevention around the world"

Professor Ivor Chestnutt, lead of the Seal and Varnish study.



A child being treated with fluoride varnish for the prevention of tooth decay

Who we are

PRIME operates an **inclusive and horizontal leadership model**, with multidisciplinary contribution to the leadership group (Directors) and Operational Working Group and support for Early Career Researchers (ECR) in leadership roles (e.g. co-leading Workpackages).

Our **all-Wales emphasis** is evident in our rotating Annual Meetings at Cardiff University, Swansea University, Bangor University and the University of South Wales.

The **Leadership group** (directors) derives substantial support and strategic direction from the "SUPER" group (patients and public), the All-Wales Steering Committee (policymakers, domain and discipline stakeholders), and the International Advisory Board (overseas academics and PPI contributors).

The PRIME Centre Wales **All Wales Steering Committee** meets twice yearly and is comprised of all co-applicants, work package and cross-cutting theme/strategy leaders, representatives from third sector and lay members.

The Committee provides advice and direction for the overall Centre strategy, together with a supportive scrutiny role, and steer for fit with government, public and professional / service priorities, and scrutiny of progress towards its milestones and outputs.

The **Operational Working Group** meets monthly and is comprised of Centre Directors, Work Package Leads and core-funded research and professional services staff. The group ensures effective cross-university collaboration of the team towards achieving the goals of PRIME.

The **International Advisory Board** provides independent advice, critical comment, international context; International experts in primary, unscheduled care research (collaborators from England, Belgium, Sweden, Canada, from primary care, public health, dental, community nursing, emergency care disciplines, and PPI contributors with international experience). Meets once per year.

The **SUPER Group** considers overall direction, patient and public priorities; Theme and project-specific proposals. 15-20 individuals recruited from Wales members of the public / general population. Meets 4 times per year.

All-Wales Steering Committee



Operational Group

 Adrian Edwards Director, PRIME Professor of Primary Care, Cardiff University	 Joyce Kenkre Associate Director, PRIME Professor of Primary Care, University of South Wales	 Helen Snooks Associate Director, PRIME Professor of Health Services Research, Swansea University	 Clare Wilkinson Associate Director, PRIME Professor of General Practice, Bangor University
 Carolyn Wallace WP1, Long-term conditions Professor of Community Health & Care Sciences, University of South Wales	 Fiona Wood WP2, Patient-centred care Reader, Cardiff University	 Natalie Joseph-Williams WP2, Patient-centred care Lecturer, Cardiff University	 Kathryn Hughes Infections & antimicrobial resistance Clinical Lecturer, Cardiff University
 Harry Ahmed Infections & antimicrobial resistance Clinical Senior Lecturer & Epidemiology, Cardiff University	 Kate Brain WP4, Screening, prevention & early diagnosis Professor of Health Psychology, Cardiff University	 Aileen Porter WP5, Emergency, unscheduled and pre-hospital care Associate Professor, Swansea University	 Andrew Carson-Stevens WP6, Patient safety Clinical Reader in Quality Improvement & Patient Safety, Cardiff University
 Ivor Chestnutt WP7, Oral health & primary dental care Professor & Hon. Consultant in Dental Public Health, Cardiff University	 Raheem Adam Study Manager, Swansea University	 Alison Cooper Clinical Research Fellow, Cardiff University	 Bride Evans Research Fellow & Lay Involvement Lead, Swansea University
 Freya Davies Clinical Research Fellow, Cardiff University	 Megan Elliott Senior Research Assistant, University of South Wales	 Julia Hiscock Research Fellow, Bangor University	 Rebecca Jane-Law Research Officer, Bangor University
 Ashia Khanom Research Officer, Swansea University	 Mark Kingston Senior Research Officer, Swansea University	 Ruth Lewis Research Fellow, Bangor University	 Rhianon Phillips Research Fellow, Cardiff University
 Harriet Quinn-Scoggins Research Associate, Cardiff University	 Richard Evans Senior Clinical Officer, Bangor University	 Neil Jenkins Research Administrator, Swansea University	 Delyth Price Research Administrator, Cardiff University
 Anne Surman Finance & Communications Officer, Swansea University	 Angela Watkins Communications & Operations Manager, Cardiff University		

International Advisory Board

	Dr Sibyl Anthierens Primary Health Care Sociologist, University of Antwerp
	Carolyn Canfield Independent Citizen-Report & Adjunct Professor University of British Columbia, Faculty of Medicine, Canada
	Professor David Conway Professor of Dental Public Health, University of Glasgow
	Professor Jommy Dale Professor of Primary Care, University of Warwick
	Professor Martin Dawes Royal Canadian Legion Professor, University of British Columbia
	Dr France Légaré Research Axis of Population Health and Positive Changing Research, CIU de Québec - Université Laval
	Professor Michael Preston-Shoot Professor Emeritus (Social Work), University of Bedfordshire
	Professor Fiona Ross CBE Professor of Research, Centre for Health and Social Care Research Kingston University London, St George's University of London
	Professor Niro Siriwardena (Chair) Professor of Primary & Prehospital Health Care, University of Lincoln
	Richard Stephens Consumer Lead, Chair Consumer Forum National Cancer Research Institute
	Professor Björn-Ove Söderud Post Retirement Professor, Prehospital emergency care University of Borås, Sweden

Work Packages

Long-term conditions & co-morbidities

Leads: Prof Joyce Kenkre & Prof Carolyn Wallace

Key activities over the last year:

- Continued development and implementation of the **Family Resilience Assessment Instrument and Tool** with all health visitors across Wales, using the FRAIT Community of Practice and looking forward to identifying innovative ways of furthering this research programme using digital technology, as well as the potential to expand this work internationally, e.g. with colleagues in India.

- Implementation and development of the **Community Nursing Research Strategy**.

- Design, approvals and set up of **social prescribing mixed-methods waitlist trials with third sector** organisations, Mind Cymru and the British Red Cross; and evaluation of the Social Services and Well-being (Wales) Act 2014.

- **Using consensus methodologies** including on studies including identifying learning needs of social prescribers, mapping to explore the complexities of managing children's care, research priorities for social prescribing, quality indicators for health visiting practice and factors for multi-agency working.

- Ongoing **capacity building** including KESS studentships, building research capacity in the third sector and supporting primary care

- **Working with industry** on the health element of the BEACON's project, to develop new products to improve recycling and prevent landfill.

Next steps:

From April 2020 this work package will be restructured as Care Closer to Communities, working on research programmes which enable patients to access care in their own communities, including in home-based health and social care services, general practice, community pharmacy, opticians and third sector organisations that provide services and support to communities.

Person centred care

Leads: Prof Fiona Wood & Dr Natalie Joseph Williams

People should have the opportunity to make **informed decisions about their care and treatment, in partnership with their healthcare professionals**. Treatment and care should take into account individual needs and preferences.

How are we helping to improve person centred healthcare?

- **Increasing capacity:** Dr Freya Davies completed her PhD on how clinicians can support patients with long term neurological problems to self-manage their condition. Dr Victoria Shepherd completed her PhD on supporting proxy decision making for adults without capacity to participate in research. Two PhD studentships are ongoing, supporting young people to become more involved in Shared Decision Making (SDM), and exploring shared decision-making and co-production in pre-conception health

- Learning from the **Making Good Decisions in Collaboration (MAGIC) Programme** has resulted in two new publications focusing on a new model of SDM (Oct, 2019, PEC) and the challenges of measuring SDM in the NHS (Aug 2019, BMJ Open)

- Ongoing large-scale **NIHR grant development** and validation of diagnostic and decision making aid for men with lower urinary tract symptoms

- Recently completed NIHR decision support grants for **breast cancer treatment options in older women** (Sheffield University) and for **people considering cataract surgery** (University Hospitals Bristol NHS Foundation Trust)

- Publication reflecting on the challenges of measuring SDM in the NHS Clinician training 'Train the Trainer Programme'. We have been working with **Public Health Wales and Improvement Cymru**, to develop and deliver a national Shared Decision Making training programme for NHS clinicians and managers.

Infections & antimicrobial resistance

Leads: Dr Harry Ahmed & Dr Kathryn Hughes

We work closely with colleagues in the Centre for Trials Research and Cardiff University School of Biosciences. We collaborate with colleagues from Public Health Wales, Public Health England, University of South Wales, Bristol University, University of Oxford, University of Southampton, and European colleagues via the GRIN Network, to produce multi-disciplinary, clinically relevant research.

Our current and upcoming research includes:

- **PACE:** A NIHR funded clinical trial looking at CRP point of care testing to help guide decisions about antibiotic treatment in acute exacerbations of COPD.

- **LUCI:** A Health and Care Research Wales funded big-data study looking a long-term outcomes of childhood urinary tract infections (UTI).

- **Urinary tract infection in older people** – An NIHR funded big-data study looking at incidence and antibiotic prescribing for UTI in older people.

- **MISSING LINK:** An exploratory study looking at immune markers and bacterial genomics in adult women with UTI symptoms.

- **SPATIAL:** Application submitted to the NIHR for a big-data study aiming to enable safer prescribing of antibiotics to patients using anticoagulant medications.

- **MISSOURI:** Application submitted to the BHF for a big-data study looking at the risk of heart attack and stroke after a urinary tract infection.

- **UTI Point-of-care diagnostic test development:** Application submitted to the MRC (led by University of South Wales) to develop a quick and reliable test to detect UTI in the community.

Screening, prevention & diagnosis in primary care

Leads: Prof Kate Brain & Prof Clare Wilkinson

Screening, prevention & early diagnosis (SPED) has continued to build on its strengths in cancer and other health priorities. Focus has been aimed at developing strategies to prevent obesity related disease and reduce harm from tobacco, increasing public awareness, and improve equitable uptake of cancer screening.

Key activities over the past year:

- Developing and evaluating **community-based strategies** for encouraging earlier cancer diagnosis and integrated prevention across tumour sites.

- Addressing the (adverse) **social gradient** in cancer.

- Increased **national and international collaborations** seeking to accelerate early diagnosis for cancer.

- Kate Brain and Grace McCutchan (colleague in our sister centre, the Wales Cancer Research Centre) have been developing our international collaborations in Vietnam through an NIH grant.

- Recruitment in the NIHR funded Cancer: **Life Affirming Survivorship support in Primary care** (CLASP) Programme hit its target of 2,500 patients recruited throughout England and Wales.

- Work is ongoing on an NIHR HSDR-funded realist evidence synthesis with co-design aiming to explain **how primary care can promote physical activity and physical function** for people with long-term conditions.

- The Cancer Research Wales funded **Diagnostic Journeys in Prostate Cancer** (DjiP) study is now well underway, with patient interviews and HCP focus groups in progress.

- The WICKED study team delivered workshops to General Practice staff across Wales with the aim of **expediting the diagnosis of cancer** improving cancer outcomes as part of the ThinkCancer! Feasibility Study.

Emergency, unscheduled & pre-hospital care

Leads: Prof Helen Snooks & Dr Alison Porter

Our core research interests: **alternative care pathways** and **reductions in ambulance conveyance** to the emergency department; **linkage of routine data** and its role in research; use of **risk prediction tools** in primary care; adoption and implementation of **new technology and working practices** in pre-hospital care; conducting research in a pre-hospital context, including the **role of patients and service users in planning and delivering research**; how and why people access the unscheduled care system.

In the last year, we have delivered research in collaboration with NHS organisations and academic partners from Wales and across the UK, including these recently completed and active projects:

- **STRETCHED** an evaluation of multi-disciplinary case management of people who are high users of 999 ambulance services (NIHR HS&DR)
- **INFORM** which is working with people who are high users of 999 ambulance services to produce guidance for their care (HCRW)
- **ARRIVE** a feasibility study of paramedics working primary care (RfPPB)
- **TIME** feasibility trial of take home naloxone for opioid overdoses in pre-hospital care (NIHR HTA)
- **PHECG2** a mixed method study of the use and impact of the Pre-Hospital 12-lead electrocardiogram (NIHR Programme Grant)
- **ERA study** examining the role of electronic records in ambulances (NIHR HS&DR)
- **HEAR study** of the health and wellbeing of asylum seekers and refugees in Wales (Public Health Wales)
- **RAPID** feasibility study of pre-hospital analgesia for patients with hip fracture (RfPPB), with the Welsh Ambulance Service

Patient safety

Lead: Dr Andrew Carson-Stevens

Patient safety is **the absence of preventable harm** to a patient during the process of healthcare delivery. In the last year, we have:

- Enabled health care organisations, policy makers and researchers to **avoid missing opportunities to learn from** unsafe care episodes by achieving clarity on what is 'avoidable harm' in primary care (NIHR Health Policy programme) and what should be reported as a 'serious medication safety incident' (International e-Delphi consensus study, Welsh Government).
- Explored **the role of data analysts** in the emerging Healthcare 4.0 'big data' era and implemented procedures for analysts to support NHS organisations identify strategic priorities for patient safety improvement (Health Foundation Advancing Applied Analytics).
- Completed major studies to **describe unsafe care** experienced by three under-researched and vulnerable societal groups:
 - patients / service users receiving opioid substitution therapies ; patients requiring advance care planning at the end of their lives; and,
 - health and social care-associated harm amongst vulnerable children.
- Carson-Stevens co-chaired roundtable discussions on the measurement, reporting and learning and surveillance of patient safety with experts, policy makers and Ministers of Health at the **World Health Organization** to prepare a Global Patient Safety Action Plan (2020-2030) in response to the World Health Assembly resolution 72.6 for 'Global action on patient safety'.
- Contributed to the development of an international patient survey via the **Organisation for Economic Cooperation and Development (OECD) Working Group** for Patient-reported Safety Outcomes.

Oral health & primary dental care

Lead: Prof Ivor Chestnutt

We work in three main areas:

- Clinical trials in **preventive dentistry**;
- Use of **antimicrobials** in dentistry;
- The **effective and efficient delivery** of primary dental care.

Key areas of success and work over the last year:

- Exploring **how technology** can be employed to improve oral health in disadvantaged adolescents.
- We have received funding to **provide evidence** to support the current reforms to how primary dental care is commissioned in Wales.
- The **international applicability** of our work has been recognised by the award of a prize from the International Association for Dental Research.
- The **PRIDA study** - working with Public Health Wales and the office of the Chief Dental Officer we are exploring how a shared decision aid can be used to agree an appropriate interval to attend the dentist.
- With colleagues in the Cardiff University School of Mathematics, we have won funding from Health and Care Research Wales to determine how a more **efficient and cost effective preventive approach** can be adopted in primary dental care in Wales – the OPTIMISE study
- The NIHR funded **BRIGHT clinical trial** (in collaboration with the Universities of Dundee, Leeds, Sheffield and York) has completed all baseline examinations, and year two examinations in the schools recruited in 2017/18 are underway.

The objective of this work is to determine the clinical and cost effectiveness of SMS messages in **encouraging behaviours conducive to good oral health in adolescents** living in disadvantaged communities.

Supportive & palliative care

Leads: Prof Annmarie Nelson & Dr Marlise Poolman

Although this work package will be new for April 2020, it signals an existing and growing research area, as well as the establishment of formal links with the **Marie Curie Palliative Research Centre**.

An estimated 23,000 people in Wales require palliative care at any one time. Non-palliative care specialists (GPs, community nurses, and paramedics) play an important role in supporting and delivering end-of-life care.

Key activities over the last year:

- Completion of the NIHR-funded **CARiAD feasibility study** on the intervention of teaching lay carers to give as-needed subcutaneous injections at home to a dying loved one. As part of the COVID-19 pandemic response, the End of Life Board requested our team to draft policy for the CARiAD package to be implemented rapidly. The NIHR fast-tracked publication in support of this work, and Welsh Government approved the new all-Wales policy in March 2020.
- We were commissioned to look at **the scope of provision of all bereavement services in Wales** using NICE guidelines. A key consideration from the results is the development of a national framework for bereavement care, to facilitate increased prioritisation of bereavement support at organisational and regional level, and equity and access across Wales.

Core activities of the new work package will include:

- **Management of common symptoms** in the last months/weeks/days of life, and service models to support this, e.g. the role of nurse prescribers, medicines management, including de-prescribing
- **Lay caregiver support**: Anticipatory education on preparing for a home death, role-extension (e.g. carer-administration of as-needed injectable medication), and evidence-based bereavement support
- **Improving awareness**, societal expectations, knowledge and acceptance of death and dying.

Annual Meeting 2019

We were delighted to welcome guests to the fifth PRIME Centre Wales Annual Meeting, held 27th November hosted by Cardiff University at Park Plaza, Cardiff.

Following our previous years' rotating focus on two of PRIME Centre Wales' research workpackages, this year's event programme with the continued theme of a spotlight on two of our workpackages. This year we featured **supportive and palliative care** and **common infections and antimicrobial resistance**.

Supportive and palliative care

Launch of new workpackage for 2020, supportive and palliative care - featuring presentations by co-leads **Annmarie Nelson**, Marie Curie Professor of Supportive and Palliative Care; Scientific Director, Marie Curie Palliative Care Research Centre; **Marlise Poolman**, Senior Clinical Lecturer, Bangor University, who offered an overview of work to date and future direction of research in PRIME.

We were honoured to welcome guest speakers:

Idris Baker, Welsh National Clinical Lead for palliative and end of life care & Consultant in Palliative Medicine who presented a Welsh Government and End of Life Board perspective of palliative and supportive care research in Wales.

Ian Lewis, Head of Strategy and Initiatives, National Cancer Research Institute talked about palliative and supportive care research in the context of primary care and the National Cancer Research Institute (NCRI).

Mr **Jim Fitzgibbon**, public member speaker for palliative and supportive care who offered a carer's/family member perspective.

Common infections and antimicrobial resistance

The common infections and antimicrobial resistance spotlight featured presentations by the two new workpackage co-leads **Kathryn Hughes** and **Harry Ahmed** who offered a contextual overview of why this research is so important, and

how PRIME's research is helping to improve diagnosis and treatment of infections optimise antibiotic use.

With guest speakers:

Rhiannon Phillips, Lecturer in Health and Wellbeing Psychology School, Cardiff Met University, and **David Gillespie**, Deputy Director of Infection, Inflammation & Immunity, Centre for Trials Research Trials, Cardiff University, to share important findings from the PACE study (published in the New England Journal of Medicine) and tell us how these were disseminated in order to inform future policy and practice.

The day closed with an **elevator pitch session**, featuring 11 presentations from a range of speakers, with a prize awarded for the top three.

Best elevator pitch to:

- **Jess Roberts**, Bangor University, for research findings pitch: CARer-ADministration of as-needed sub-cutaneous medication for breakthrough symptoms in homebased dying patients: a UK study protocol (CARIAD)

Runner-up to:

- **Pamela Smith**, Cardiff University for research findings pitch: Recruitment of hard-to-reach smokers using a novel social media strategy
- **Chris Moore**, Welsh Ambulance Service Trust for dangerous idea pitch 'Prehospital Recognition and Antibiotics for 999 patients with Sepsis (PhRASE): Feasibility Study Interim Results'

Posters profiling PRIME led and supported research projects were also displayed. A selection of these along with the full programme is also available to view on the PRIME website.

The event was well received by guests with positive feedback from delegates (see opposite for quotes).



"Very worthwhile. Learnt a lot. Appreciated the opportunity to meet new colleagues and share in their work."

"Learning all the time - good!"

"Enjoyed the posters that covered each work package and then provided more detail about selected projects."

"Excellent to see the level of commitment and application that PRIME has."

"I think as an AGM the format is great. Lots of people involved loads of presentations and posters etc., which shows PRIME off to be a very vibrant research and practice based community. Great stuff!"

Excellent organisation, very good balance between talks/workshops/breaks. Great research."

Public involvement

Within PRIME, we continue to drive forward further public involvement in our activities of planning, delivering and disseminating research which seeks to benefit patient care and outcomes.

Our intention is that **all research will involve public contributors** so that the perspectives of people who receive health, care and emergency services in the community are considered throughout.

The stable, well resourced infrastructure provided through PRIME Centre Wales has enabled all those involved to **build strong relationships and embed diverse approaches** to public involvement and engagement.

Researchers and public contributors have been able to **commit to collaborations, develop knowledge and skills and sustain relationships over time**.

The **SUPER group** remains the regular forum for all PRIME researchers to discuss research projects with public contributors. SUPER holds quarterly face to face meetings in June, September, November and March. In the past year, researchers presented a variety of projects for discussion with group members.



SUPER members Lindsay Heywood and Barbara Harrington, leading the SUPER workshop at the PRIME Annual Event in November 2019

Topics have included: how to engage with smokers and involve them in research about smoking cessation; important issues when undertaking research about dying; language and communication when planning research about patients' adherence to medication; questions to consider when planning a study about treating people with mental health emergencies who call 999.

In all discussions, SUPER members provided **insight and observations** which reflected personal experiences and knowledge from the **diverse networks** they are part of and from their own lives.

SUPER gives researchers an insight into **the reality of living with and alongside health challenges** and access to that knowledge to benefit research. Researchers who have worked with SUPER say they gain input which is different from other team members' contributions.

'Really useful – SUPER answered all my queries and raised additional important points that I had not considered... used to revise and improve the grant application'

'... a wider understanding of perceptions of services, highlighted challenging elements of the research task, and provided food-for-thought regarding further and future opportunities'

'My application was successful, and this will have been achieved because of your support and input'

Feedback to researchers is also provided between meetings via email. Some SUPER members have additionally chosen to work in research teams as **co-applicants and collaborators** on funded studies.

Public contributors including SUPER members also attended stakeholder events held by PRIME studies – the ARRIVE project about paramedics in general practice; the PERCH project about paramedics in care homes; and the GPs in Emergency Departments project.

These were opportunities to consider aspects of project development and implementation from

the perspective of patients and carers. These events were **all jointly organised and hosted with the public contributors** who are involved in these projects.

SUPER members also comment on and contribute to **all PRIME public facing documents** – including this annual report. In contributing to this document, they suggested additional information, ways to improve the clarity of text and where to include tables or figures to aid interpretation.

SUPER held its annual meeting in September 2019 and elected **Mari James** to chair the group. She succeeds **Roger Morley-Jones** who was **warmly thanked** for leading SUPER during the previous three years.

Public involvement was featured at the PRIME annual meeting in November 2019 in talks and poster presentations. Public contributor Jim Fitzgibbon was one of the guest speakers showcasing the new Palliative and Supportive Care workpackage.

Among winners of the Elevator Pitch session, chaired by public member Roger Morley-Jones, was a presentation about an innovative social media approach to engage smokers in research.

SUPER members delivered one of the workshop sessions entitled 'No research about us without us: how public and patient involvement is essential in PRIME research'.

PRIME researchers have also accessed public input to their research activities through the **Public Involvement Community in Wales** which is supported by Health and Care Research Wales' Support Centre.

Public contributors are involved in planning and submitting research proposals, implementing research studies and disseminating findings through jointly prepared reports, presentations and publications.

The **HEAR project** about the health needs of asylum seekers and refugees was recognised for its innovative approach to involving and engaging with people seeking sanctuary in Wales. Dr Ashra



Mari James and Roger Morley-Jones, the current and past chairs of SUPER

Khanom and her team of peer researchers and public collaborators won the 2019 Public Involvement Achievement Award.

Study design and data collection methods in this innovative project were closely guided by the **experiences of asylum seekers and third sector organisations** who trained people from participating communities to administer questionnaires in different languages.

Public members also joined a dissemination event, showcasing study findings to policy makers and practitioners including Wales' Chief Medical Officer Dr Frank Atherton.



SUPER members congratulating Dr Ashra Khanom on receiving the 2019 Public Involvement Achievement Award

Key outputs & emerging outcomes

Key research findings from PRIME research published 2019-20:

WP1. Long-term conditions & co-morbidities

Developing a family resilience assessment tool for health visiting/public health nursing practice

UK health visitor/public health nurse (PHN) assessment of family resilience has become a necessary component of monitoring family health and children's developmental outcomes, and identifying areas for intervention. The research reported here was part of an in-depth exploration of Welsh PHNs' understanding of family resilience as a concept underpinning their practice.

This led to the development of the Family Resilience Assessment Instrument Tool (FRAIT www.frait.wales) and training package for use by PHNs in everyday practice. Welsh Government has incorporated FRAIT into the universal provision of PHN services in Wales as described in the Healthy Child Wales Programme.

The second stage of the FRAIT study was to evaluate FRAIT through simulation using a virtual commissioning design from engineering. A high-fidelity immersive simulation suite (Hydra-Minerva) and focus groups were used to road test a FRAIT prototype in a safe, controlled environment before field testing.

Family resilience as used in FRAIT offers an original contribution to the international literature on PHN practice. It draws on the theoretical and practice background of PHNs, where the focus is on the resilience of families as a single unit due to the social interdependence of individual family members within the family unit.

FRAIT considers family strengths, resources and concerns as a means to support productive positive behaviour, and in doing so operationalizes the four principles of UK PHN practice: searching for health needs; stimulating of an awareness of health needs; influencing policies affecting health; and facilitating

health-enhancing activities. This is a re-conceptualisation of PHN practice in Wales and further work is required to identify the practice issues that such a change makes to working with families.

The team found that developing relevant practice evidence for use by practitioners is challenging. There is scope for using virtual commissioning when carrying out translational research such as this to overcome some of these challenges of physical commissioning.

Pontin D, Thomas M, Jones G, O'Kane J, Wilson L, Dale F, Whitcombe D, Wallace C. Developing a family resilience assessment tool for health visiting/public health nursing practice using virtual commissioning, high-fidelity simulation and focus groups. *Journal of Child Health Care*, July 2019, <https://doi.org/10.1177/1367493519864743>

Using consensus methods to develop a Social Prescribing Learning Needs Framework for practitioners in Wales

Social prescribing (SP) is, 'a process to help people make positive changes in their lives and within their communities by linking people to volunteers, activities, voluntary and community groups and public services'.

Its purpose is to improve individual well-being and support people to take greater control of their lives by addressing the bio-psychosocial and environmental context.

SP is being widely implemented across Wales. Health and social care is devolved to Welsh Government (WG), and they have commissioned SP prevention and early intervention service pilots in mental health.

There are a number of SP models used in Wales. Most include a general practitioner (GP) practice or a community-based support worker having a 'what matters conversation' with individuals, co-producing personal goals and action plans, and connecting people to community resources.



A video has been developed to publicly share the results of the DECISION study <https://youtu.be/uHg3SydNXAI>

Across Wales, the complexity is exacerbated as the different programmes are managed by the health sector, social care, or 3rd sector providers. There is limited agreement on SP competency, and training and education needs and provision.

Due to the complexity of commissioning arrangements and focus on localism, SP has developed organically in Wales to meet local needs, such that current roles have different skill requirements and employment scales.

Consequently, there has been no consensus on the required learning needs to demonstrate competency.

The purpose of this study was to develop an education and training needs conceptual framework for SP in Wales, which commissioners and providers could use to develop SP curricula and competency assessment frameworks, regardless of employing authority.

This is the first UK study to explore the learning

needs identified by social prescribers. Using two different consensus methods allowed geographically dispersed social prescribers to engage with the study.

The Social Prescribing Learning Needs Framework will be used to inform the commissioning and decommissioning of education and training for people delivering SP in Wales.

Future research might wish to evaluate the implementation of training, focus on training needs timeliness and investigate the preferred format in which social prescribers wish to receive this training.

Wallace C, Elliott M, Thomas S, et al (2020) Using consensus methods to develop a Social Prescribing Learning Needs Framework for practitioners in Wales. *Perspectives in Public Health*. doi.org/10.1177/1757913919897946

WP2. Person centred care

Adolescents' perceptions around barriers and facilitators to Shared Decision Making

Adolescents living with long-term conditions (LTCs) often feel as though they are left out of discussions and decisions with healthcare professionals, which can give them the impression that their views are not important.

Research around decision-making during clinical encounters often fails to represent adolescents' perspectives. This study explores adolescents' perceptions and experiences, focusing on identifying the perceived barriers to, and facilitators for, their involvement in shared decision-making (SDM).

Adolescents with LTCs were recruited from endocrinology, rheumatology, neurology, and nephrology clinics and interviewed.

The team identified four overarching themes and nine sub-themes which describe barriers and facilitators around SDM.

Adolescents need to feel, as though their involvement is supported by parents and healthcare professionals, that their contribution to the decision-making process is important and will yield a positive outcome.

Adolescents often feel it is their right to be involved in decisions that affect them but also feel as though the adults' contributions to the decisions are considered more valuable.

Adolescents need to feel capable of being involved, in terms of being able to understand and process information about the available options and ask appropriate questions.

This work highlights a number of ways SDM can be facilitated between healthcare practitioners and adolescents with LTCs. Identifying the needs of adolescents with LTCs is necessary for optimizing the SDM process and to support them during healthcare consultations.

Jordan A, Joseph-Williams N, Edwards A, Holland-Hart D, Wood F. "I'd like to have more of a say because it's my body": Adolescents' perceptions around barriers and facilitators to Shared Decision Making. *J. Adolesc. Health*, 2019, <https://doi.org/10.1016/j.jadohealth.2019.05.024>

Proxy decision-making for research involving adults who lack capacity to consent

Research into dementia and other conditions connected with cognitive impairments is essential but conducting research with populations who lack capacity to provide consent involves a number of ethical, legal and practical challenges.

In England and Wales, family members can act as a consultee or legal representative on behalf of someone who lacks capacity.

However, there is a paucity of research about how family members make decisions concerning research participation.

This study aimed to explore family members' experiences of proxy decision-making for research.

Understanding how proxy decisions are made could lead to interventions to support greater inclusion of individuals in research who have impaired decision-making capacity.

The researchers conducted a thematic analysis of semi-structured interviews with a purposive sample of 17 family members who had experience as a proxy for making decisions about participation in research, including those who had agreed to participation and those who declined.

The study found that proxy decision-making for research is a complex process with inter-woven layers of decision-making.

Decisions can be problematic for some proxies who may benefit from decision support to make an informed decision about research participation on behalf of a family member.

Shepherd V, Hood K, Sheehan M, Griffiths M, Wood F. 'It's a tough decision': a qualitative study of proxy decision-making for research involving adults who lack capacity to consent in UK, Age and Ageing, 48:6, 2019, 903–909 <https://doi.org/10.1093/ageing/afz115>

WP3. Infections & antimicrobial resistance

What the public think about participation in medical research during an influenza pandemic: an international cross-sectional survey

The public and patients are primary contributors and beneficiaries of pandemic-relevant clinical research. However, their views on research participation during a pandemic have not been systematically studied. We aimed to understand public views regarding participation in clinical research during a hypothetical influenza pandemic.

We surveyed the views of nationally representative samples of people in Belgium, Poland, Spain, Ireland, the United Kingdom, Canada, Australia and New Zealand, using a scenario-based instrument during the 2017 regional influenza season. Descriptive and regression analyses were conducted.

Our study indicates current public support for pandemic-relevant clinical research. Tailored information and initiatives to advance research literacy and maintain trust are required to support pandemic-relevant research participation and engagement.

Gobat N, Butler CC, Mollison J, et al. What the public think about participation in medical research during an influenza pandemic: an international cross-sectional survey. *Public Health*. 2019; 177: 80-94. <https://doi.org/10.1016/j.puhe.2019.07.005>

Impact of antibiotic treatment duration on outcomes in older men with suspected urinary tract infection

Clinical guidelines recommend at least 7 days of antibiotic treatment for older men with urinary tract infection (UTI).

There may be potential benefits for patients, health services, and antimicrobial stewardship if shorter antibiotic treatment resulted in similar outcomes.

We aimed to determine if treatment duration could be reduced by estimating risk of adverse outcomes according to different prescription durations.

What members of the public think about taking part in medical research during a pandemic of an influenza-like illness: a study across four European countries

REPORT FOR STUDY PARTICIPANTS



A plain text booklet was produced to share the results of the PREPARE public survey

We showed, for the first time, that in older men presenting to primary care with a UTI, 3-day antibiotic treatment was associated with a 52% increase in odds of reconsultation and represcription that may indicate treatment failure or recurrent infection but was not associated with increased odds of UTI-related hospitalisation or death.

We also showed for the first time, an association between 3-day treatment and a 38% reduction in the odds of hospitalisation for AKI.

Our findings suggest it may be possible to safely reduce the duration of antibiotic treatment to 3 days for older men presenting to primary care with a UTI.

For patients, shorter duration treatment could mean better adherence and less side effects.



A video has been developed to publicly share the results of PACE <https://youtu.be/AtZ7bnbp0Nk>

Ahmed H, Farewell D, Francis NA, et al. Impact of antibiotic treatment duration on outcomes in older men with suspected urinary tract infection: Retrospective cohort study. *Pharmacoepidemiol Drug Saf.* 2019; 28: 857– 866. <https://doi.org/10.1002/pds.4791>

C-Reactive Protein Testing to Guide Antibiotic Prescribing for COPD Exacerbations

More than a million people in the UK have COPD, which is a lung condition associated with smoking and other environmental pollutants.

People living with the condition often experience exacerbations, or flare-ups, and when this happens, three out of four are prescribed antibiotics. However, two-thirds of these flare-ups are not caused by bacterial infections and antibiotics often do not benefit patients.

Primary care providers are responsible for the majority of antibiotic prescriptions, and the highest overall number of such prescriptions are issued by family physicians.

There is reason to believe that many of these prescriptions could be avoided. Unwarranted use of antibiotics drives antimicrobial resistance, wastes resources, may cause adverse effects, and

negatively affects the microbiome of patients.

A finger-prick test can measure the amount of C-reactive protein (CRP) - a marker of inflammation that rises rapidly in the blood in response to serious infections. People with a COPD flare-up who have a low CRP level in the blood appear to receive little benefit from antibiotic treatment.

The team demonstrated that using a CRP finger-prick blood test resulted in 20% fewer people using antibiotics for COPD flare-ups.

Importantly, this reduction in antibiotic use did not have a negative effect on patients' recovery over the first two weeks after their consultation at their GP surgery, or on their well-being or use of health care services over the following six months.

Butler CC, Gillespie D, White P, et al. C-Reactive Protein Testing to Guide Antibiotic Prescribing for COPD Exacerbations. *N Engl J Med* 2019; 381:111-120 <https://doi.org/10.3310/hta24150>

WP4. Screening, prevention & diagnosis in primary care

Engaging high-risk groups in early lung cancer diagnosis

People at high-risk for lung cancer - current/former smokers, aged 40+ years, with serious lung comorbidity (ie, chronic obstructive pulmonary disease) and living in highly deprived areas - are more likely to delay symptom presentation.

This qualitative study aimed to understand the influences on early presentation with lung cancer symptoms in high-risk individuals and intervention preferences.

The researchers used semi-structured qualitative interviews and focus groups with high-risk individuals identified through seven GP practices in socioeconomically deprived, and local stakeholders (healthcare professionals and community partners) to explore lung symptom perception and help seeking behaviour, and preferences for an intervention to promote early lung cancer symptom presentation.

They concluded that perceived lack of health service entitlement and complex lives facilitated avoidance of recognising and presenting with lung cancer symptoms.

Community-based interventions have the potential to empower disadvantaged populations to seek medical help for lung symptoms.

This study was novel in engaging a high-risk population to gain an in-depth understanding of the broader contextual influences on lung cancer symptom presentation.

The study findings featured in the UK Lung Cancer Coalition report *Early Diagnosis Matters, Making the Case for the Early and Rapid Diagnosis of Lung Cancer*. 30 January 2020. uklcc.org.uk

McCutchan G, Hiscock J, Hood K, Murchie P, Neal R, Newton G, Thomas S, Thomas AM, Brain K. Engaging high-risk groups in early lung cancer diagnosis: a qualitative study of symptom presentation and intervention preferences amongst the UK's most deprived communities. *BMJ Open* 2019;9:e025902. <http://dx.doi.org/10.1136/bmjopen-2018-025902>

Behavioural smoking cessation interventions for older smokers from deprived backgrounds

Smoking is the leading global cause of death and disease and data show that there are approximately 7.4 million adult cigarette smokers in the UK.

Twenty-six per cent of smokers in the UK are aged 50 years or older; these individuals tend to have long standing smoking histories, are often from deprived communities and are a population that are likely to be eligible for future lung screening implementation.

The associations between smoking prevalence, socioeconomic group and a range of chronic disease outcomes, including lung cancer outcomes are well established, with higher smoking rates and greater lung cancer incidence and mortality among people living in deprived areas.

This systematic review is the first to examine the influence of behavioural smoking cessation interventions (SCIs) for an older, deprived population.

It demonstrates the potential for tailored, multimodal SCIs for older, deprived smokers that can be embedded within disadvantaged communities.

With the prospect of lung cancer screening being implemented in the UK and Europe in the near future, this research adds to the evidence base regarding promising SCIs for older, deprived populations who will benefit most from lung screening and integrated smoking cessation support.

Smith P, Poole R, Mann M, Nelson A, Moore G, Brain K. Systematic review of behavioural smoking cessation interventions for older smokers from deprived backgrounds. *BMJ Open* 2019;9:e032727. <http://dx.doi.org/10.1136/bmjopen-2019-032727>

WP5. Emergency, unscheduled & pre-hospital care

Rapid Analgesia for Prehospital hip Disruption (RAPID): findings from a randomised feasibility study

Hip fracture is a common, very painful injury, particularly affecting vulnerable elderly people.

Hip fractures generate more admissions to orthopaedic trauma wards than any other injury, and an average inpatient stay of 21 days, thus accounting for 2.5% of all hospital beds.

In managing hip fracture, effective pain relief before admission to hospital is difficult without risking side effects.

Although emergency departments routinely use fascia-iliac compartment block (FICB), there has been little evaluation of its use by paramedics before hospital admission.

We aimed to assess whether a multi-centre randomised trial to evaluate FICB was feasible. Volunteer paramedics used scratch cards to allocate patients with hip fracture at random between FICB and pain relief as usual.

We also measured adverse events, costs, final diagnosis, length of stay in hospital, pain scores and quality of care and collected qualitative data about acceptability to patients in interviews, and paramedics in focus groups.

We pre-specified criteria for deciding whether to progress to a fully powered trial based on the recruitment of paramedics and patients, delivery of FICB, retrieval of outcome data, safety, acceptability, and diagnostic accuracy of hip fracture.

As equipoise remains, we plan to undertake a fully powered multi-centre trial to test clinical and cost effectiveness of paramedic-administered FICB at the scene of hip fracture.

Jones JK, Evans BA, Fegan G, et al. Rapid Analgesia for Prehospital hip Disruption (RAPID): findings from a randomised feasibility study. Pilot and Feasibility Studies, 2019;5:77.
<https://doi.org/10.1186/s40814-019-0454-1>

What are emergency ambulance services doing to meet the needs of people who call frequently?

Emergency ambulance services are integral to providing a service for those with unplanned urgent and life-threatening health conditions. However, high use of the service by a small minority of patients is a concern.

Our objectives were to describe: service-wide and local policies or pathways for people classified as Frequent Caller; call volume; and results of any audit or evaluation.

We conducted a national survey of current practice in ambulance services in relation to the management of people who call the emergency ambulance service frequently using a structured questionnaire for completion by email and telephone interview. We analysed responses using a descriptive and thematic approach.

We found that ambulance services are under pressure to meet challenging response times for high acuity patients.

Tensions are apparent in the provision of care to patients who have complex needs and call frequently.

Multi-disciplinary case management approaches may help to provide appropriate care, and reduce demand on emergency services.

Snooks HA, Khanom A, Cole R, Edwards A, Edwards BM, Evans BA, Foster T, Fothergill RT, Gripper CP, Hampton C, John A, Petterson R, Porter A, Rosser A, Scott J. What are emergency ambulance services doing to meet the needs of people who call frequently? A national survey of current practice in the United Kingdom. BMCEmergMed 19, 82 (2019)
<https://doi.org/10.1186/s12873-019-0297-3>



Research collaboration with the Welsh Ambulances Services Trust to investigate the most effective way of using electronic health records in ambulances

Electronic Health Records in Ambulances: The ERA Multiple-Methods Study

Ambulance services have a vital role in the shift towards the delivery of health care outside hospitals, when this is better for patients, by offering alternatives to transfer to the emergency department.

The introduction of information technology in ambulance services to electronically capture, interpret, store and transfer patient data can support out-of-hospital care.

We aimed to understand how electronic health records can be most effectively implemented in a pre-hospital context in order to support a safe and effective shift from acute to community-based care, and how their potential benefits can be maximised.

We found limited literature on electronic health records. Only half of the UK ambulance services had electronic health records in use at the time of

data collection, with considerable variation in hardware and software and some reversion to use of paper records as services transitioned between systems.

Realising all the benefits of electronic health records requires engagement with other parts of the local health economy and dealing with variations between providers and the challenges of inter-operability.

Clinicians and data managers, and those working in different parts of the health economy, are likely to want very different things from a data set and need to be presented with only the information that they need.

Porter A, Badshah A, Black S, et al. Electronic health records in ambulances: the ERA multiple-methods study. Southampton (UK): NIHR Journals Library; 2020 Feb. (Health Services and Delivery Research, No. 8.10.) Available from: <https://doi.org/10.3310/hsdr08100>

WP6. Patient safety

Identifying 'avoidable harm' in family practice

Health care-related harm is an internationally recognized threat to public health and wellbeing.

There is a global transition towards primary care-led health care systems, and countries like the United Kingdom demonstrate upwards of 90% of care encounters can be delivered in ambulatory settings.

As other countries transition to emulate those with predominantly extended family practice-based care models, a clear understanding of avoidable harm is needed to enable health care systems to identify and learn from the most serious incidents and the contributory factors amenable to intervention.

A recent systematic review investigating the frequency and burden of harm in family practice concluded 2–3% of primary care encounters involve a health care-related error, and around one in 25 of those result in a significant harm outcome that has a substantial impact on a patients' well-being.

The WHO has recognised that standardised definitions of core terminology needs to be developed to permit the identification of health care-related harms in primary care and comparisons across settings, countries and over time. We aimed to define "avoidable harm" to be used in future observational studies in family practice.

From our analysis of avoidable harm scenarios, we derived a definition of avoidable harm in the context of family practice.

This has potential to support researchers and practitioners to clarify the scope of inquiry needed to determine the frequency and burden of unsafe family practice.

It also enables an international comparison of findings that should accelerate the pace of learning to design and implement interventions to improve patient safety across a range of FP contexts and economic circumstances.

Carson-Stevens A, Campbell S, et al. Identifying 'avoidable harm' in family practice: A RAND/UCLA Appropriateness Method consensus study. *BMC FamPract*20, 134 (2019) doi.org/10.1186/s12875-019-0990-z

Patient safety incidents in advance care planning for serious illness

Advance care planning (ACP) is essential for patient-centred care in the last phase of life. There is little evidence available on the safety of ACP. This study characterises and explores patient safety incidents arising from ACP processes in the last phase of life.

The National Reporting and Learning System collates patient safety incident reports across England and Wales.

Mixed-methods, combining structured data coding, exploratory and thematic analyses were undertaken to describe incidents, underlying causes and outcomes, and identify areas for improvement.

This national analysis identifies priority concerns and questions whether it is possible to develop strong system interventions to ensure safety and quality in ACP without significant improvement in human-dependent issues in social programmes such as ACP.

Further work should focus on measuring the impact of improvement activities targeting ACP human-dependent and systems elements to improve the safety of care for patients in the last phase of life.

Our findings question whether it is possible to develop strong system interventions to ensure safety and quality in ACP without significant improvement in human-dependent concerns such as patient, carer and professional understanding of ACP and the trustworthiness of enacting prior ACP.

Achieving this should be explored in local contexts alongside systems development for recording and accessing ACP documents so that quality as well as quantity of ACP usage improves.

Rigorous evaluation of ACP initiatives is needed, with dissemination of results to ensure the safest, highest quality and most effective models can be replicated and adapted to local contexts.

Dinnen T, Williams H, Yardley S, et al. Patient safety incidents in advance care planning for serious illness: a mixed-methods analysis. *BMJ Supportive & Palliative Care*, 2019. dx.doi.org/10.1136/bmjspcare-2019-001824

WP7. Oral health & primary dental care

The acceptability of fluoride varnish and fissure sealant treatments in children aged 6-9 delivered in a school setting

This study aimed to assess the acceptability of fluoride varnish and fissure sealant treatments for children delivered in a school setting.

Participants were children aged 6-9, their parents, clinical staff and school staff. Interventions: Fluoride varnish or fissure sealant was delivered to children from the ages of 6 to 9 years for 36 months, by a community dental service in a school setting.

Fluoride varnish was re-applied every 6 months; fissure sealant was applied once to first permanent molars and re-applied as required.

Our interviews with children a few days after treatment indicated little difference in preference; acceptability at this point was driven by factors such as finding it fun to visit 'the van' (i.e. mobile dental unit) and receiving a "sticker" (see below) rather than specific treatment received.

Interviews with parents, clinicians and school staff indicated high acceptability of delivering this type of intervention in a school setting; this may have been partly due to the service being delivered by a well-established, child-oriented community dental service which delivered the clinical trial.

This study found that preventive fluoride varnish and fissure sealant treatments in a school setting has high overall acceptability.

Morgan-Trimmer S, Chadwick BL, et al. The acceptability of fluoride varnish and fissure sealant treatments in children aged 6-9 delivered in a school setting. 2019 *Community Dent. Health* 36(1):33-38. DOI: 10.1922/CDH.4263Morgan-Trimmer06



Using routinely collected data to produce antibiotic prescribing profiles for general dental practitioners in Wales

Since the introduction of individualised prescription pads for dental practitioners in Wales in 2011 and the launch of an educational audit a year later, antibiotic prescribing by dentists in Wales has decreased by approximately 22%.

However, evidence suggests there is still room for improvement. This project was undertaken as a step towards developing a sustainable system of providing feedback on antibiotic prescribing in primary dental care in Wales.

Providing dentists with feedback on their antibiotic prescribing is only one part of promoting antimicrobial stewardship within the profession.

It is also important to account for complex factors that influence the antibiotic prescribing behaviours of dental practitioners such as perceived patient expectation and pressures of time and workload.

The key learning points for the dental public health team from this work are that it is important to work with key partners over a period of time to:

- develop a system that produces meaningful antibiotic prescribing profiles; and
- subsequently make meaningful use of antibiotic prescribing profiles to improve the use of these important agents in dental care.

Cope AL, Roper R, Chestnutt IG, Karki AJ. Exploring the feasibility of using routinely collected data to produce antibiotic prescribing profiles for general dental practitioners in Wales. *Community Dent. Health* (2019) 36, 177–180. doi.org/10.1922/CDH.4211Cope04

Research impact, highlights & awards

'Seal or Varnish?' dental study receives prestigious award

Ivor Chestnutt, Joint Acting Head of School, Professor and Hon. Consultant in Dental Public Health, and Associate Dean for Postgraduate Studies, was awarded the 2019 International Association of Dental Research (IADR) award for best paper published in the Journal of Dental Research.

Professor Chestnutt, is also the Research lead for Primary Dental Care in PRIME, and Specialty Lead for oral and dental health for Health and Care Research Wales. He received the prestigious William J. Gies Award for the 'Seal or Varnish?' study, run through the Health and Care Research Wales funded Centre for Trials Research at Cardiff University.

The 'Seal or Varnish?' study, in collaboration with Cardiff and Vale University Health Board Community Dental Service, treated just over 800 children with either fissure sealants or fluoride varnish to discover which treatment is most effective and offers the best value for money for children aged 6-7 years.

The team found that applying fluoride varnish to children's teeth is just as effective at preventing tooth decay as the alternative method of sealing teeth and could save the NHS money. Professor Chestnutt, who led the study, commented:

"This award demonstrates that we have the capacity in Wales to conduct impactful research that has implications for dental prevention, not only locally, but across the world."

"This work was facilitated by close collaboration between the NHS and Cardiff University and is just recognition of the tremendous efforts of a large team of clinical and research staff, in seeing the work to completion."



Pictured is Professor Chestnutt (third left) receiving the award from Professor Rena D'Souza, President of the International Association for Dental Research, Prof William Giannobile, Editor of the Journal of Dental Research, and Professor Maria E. Ryan, President of the American Association for Dental Research

Assistance from Health and Care Research Wales in relation to funding and governance aspects of the work was also key to successful delivery of the research. The award winning paper and full trial report of the trial is available for the public to view open access.

Chestnutt IG, Playle R, Hutchings S, Morgan-Trimmer S, Fitzsimmons D, et al. "Fissure Seal or Fluoride Varnish? A Randomized Trial of Relative Effectiveness." Journal of Dental Research 96, no. 7 (July 2017): 754–61. doi:10.1177/0022034517702094.

Welsh GP surgeries take part in national study

A total of 328 patients from 33 Welsh GP surgeries have taken part in a recent study that found a simple finger-prick blood test could prevent unnecessary prescribing of antibiotics to people with chronic obstructive pulmonary disease (COPD).

Over one million people in the UK have COPD, a condition that affects the lungs and causes difficulties breathing, and over 80 percent of these patients are prescribed antibiotics when they have exacerbation of their symptoms. However, in two thirds of cases antibiotics have no effect on their condition.

The 'Point of care testing to target antibiotics for chronic obstructive pulmonary disease exacerbations' (PACE) study, involving researchers from the Centre for Trials Research and the Wales Centre for Primary and Emergency Care Research (PRIME Centre Wales), aimed to reduce antibiotic consumption without negatively impacting on COPD patients' condition.

Working with GP surgeries across England and Wales, PACE found that by giving a finger-prick test that measures the amount of C-reactive protein (CRP) – a marker of inflammation that rises rapidly in the blood in response to serious infections – researchers could reduce the number of antibiotics prescribed by 20 percent, without there being any negative effects for patients.

Michelle Morgan, Research Assistant at Llan Healthcare, one of the practices that took part in the study, said:

"Being new to research, this was the very first study that I had worked on. Knowing that COPD was on the rise, that antibiotics were being so over prescribed, and that we may one day all develop antibiotic resistance, it was great to be part of a study to see whether a simple blood test would help clinicians in the future decide whether or not to prescribe antibiotics."

"Within our practice we found patients were very willing to participate in the PACE study, as they felt confident that they were getting a test done, which actually gave them the result there and then.

"Safely reducing the use of antibiotics in this way may help in the battle against antibiotic resistance".

Health and Care Research Wales funded research nurses were also involved in patient recruitment and data collection for the PACE study, which has been published in the New England Journal of Medicine.

The publication has prompted a review of the National Institute for Health and Care Excellence guidelines, and the study team aims to inform new Global Initiative for Chronic Obstructive Lung Disease guidelines for the management of COPD.



Finger-prick blood tests were used by in GPs to help guide antibiotic prescribing in the PACE study

Hearing everyone's voices: engaging and involving asylum seekers and refugees in the HEAR study

Numbers of asylum seekers and refugees (AS&Rs) in Wales are increasing, but we know little of their healthcare experiences. A team of PRIME researchers from Swansea University Medical School worked collaboratively with AS&Rs themselves, with Public Health Wales (PHW) and the third sector on HEAR: The Health Experiences of Asylum Seekers and Refugees in Wales to investigate the health, well-being and healthcare experiences of adult AS&Rs in Wales.

This mixed methods study gathered information from 210 questionnaires; eight focus groups with 57 AS&R participants; and telephone interviews with 32 health and care professionals, in order to gather a rounded picture of what helped or hindered this patient group in accessing healthcare, and the experience of receiving and delivering care.

We embedded engagement in HEAR from the outset. Two lay members from the asylum seeking community joined the research team as Public and Patient Involvement members.

They provided valuable insights into how we could ensure that we were able to include data from as many participants as possible from across this diverse population, and guided us on sensitive matters.

In addition, we recruited eight asylum seekers (four men and four women, including the two lay members) as volunteer peer researchers and trained them to administer our survey in six languages, utilising their valuable trusted community links.

We cemented the strategic partnerships developed through the HEAR study at a stakeholder event, where we shared the results with health professionals, policymakers and members of the AS&R community, and discussed next steps.

During the event, the Chief Medical Officer for Wales, Dr Frank Atherton presented the peer researchers with certificates and plaques to acknowledge their contribution to the study.

The peer researchers also took part in group discussions, speaking on equal terms with health professionals about actioning study findings.



The HEAR report looks at the experiences of people seeking sanctuary of health and healthcare services from multiple perspectives, and is the largest exploring this topic in Wales

The study has already had impact:

- In response to the study finding that many women were not able to access antenatal or parent craft classes as a result of being moved from place to place by the Home Office, PHW has purchased an online parenting resource and are piloting the Arabic and English version. This resource will also address the language barriers being experienced by some of the new refugees from Syria.
- PHW are developing an online training programme aimed at health practitioners to increase their understanding of the needs of AS&Rs and their entitlements to care. The Royal College of General Practitioners in Wales has asked us to deliver a half-day workshop with PHW to talk about the study and to showcase the e-learning module.
- The lead nurse manager of the Health Access Team (service for asylum seekers) in Swansea has introduced new weekly drop-in sessions for asylum seekers with

queries about accessing services. The team will also use the time to call up patients to check that they are OK and are able to attend their GP appointments.

- The new BMA toolkit for addressing the needs of asylum seekers and refugees includes the HEAR report.
- HEAR has received three awards - from Health and Care Research Wales, Royal College of General Practitioners, and Swansea University.

Finally, one of the peer researchers is now working at Swansea University as a data analyst. He said: "I gained confidence and skills joining the HEAR team. Now I'm working in the SAIL databank as an assistant research manager [Swansea University], the dream job!"

Our HEAR study report (full and short versions) are freely available online on the websites of PHW and PRIME Centre Wales, as well as from the British Medical Association and NICE: National Institute of Health and Care Excellence.

Conclusions & future priorities

Centre funding renewed

This year, we were delighted to secure a **further five years funding from Health and Care Research Wales through Welsh Government**, to support this vital part of the Wales research infrastructure through an open competitive process.

PRIME's unique multi-disciplinary collaboration is a **single research community across Wales researching primary and emergency care** in Wales to achieve important benefits to our group, the NHS, Welsh Government and the people of Wales, through:

1. Creating a **centre of excellence** in primary and emergency care, crucial for attracting prestige research funding into Wales and providing a strong academic base for primary and emergency care
2. Delivering **high quality research** that addresses increasingly complex challenges encountered in primary and emergency care
3. Adopting an **integrated whole-systems approach** to improve services, working at the critical interface between primary, emergency, and social care
4. Ensuring clear **"pathways to impact"** plans are developed and implemented to maximise public and patient benefit from our research, including a high level of engagement, research co-production and knowledge exchange with all our stakeholders
5. **Building capacity** for primary and emergency care research in Wales, including development of research methods, skills, patients and members of the public and the workforce.

This will include the development of new principal investigators and support for clinicians in becoming research leaders. This will ensure that we can continue to have a strong academic base for primary and emergency care services in Wales in the future

PRIME will **benefit the NHS and people of Wales** by providing a strong academic and evidence base to underpin primary and emergency care.

Our collaborative work between leading academics, individuals, communities, and organisations is essential in **co-producing large-scale high-quality research with impact**.

This will underpin improvements to primary and emergency services, bringing innovative services closer to communities, empowering patients and families in their care, making services more integrated and person-centred, and ensuring that the population of Wales receives the greatest benefit from the health and social care resources available by adopting an equitable and value-based healthcare approach.

Research themes

Over the next five years, we will continue to deliver significant health and care impact, working across three high-priority policy-relevant themes:

1. Value-based primary and emergency health care

Value-based healthcare aims to provide the best value healthcare for a population using available resources.

This aligns with the 'prudent healthcare' principles of caring for those with the greatest need first, doing only what is needed, doing no harm, and reducing inappropriate variation by using evidence-based approaches.

2. Seamless health and social care closer to home

Providing seamless health and social care closer to home is a Welsh Government priority. Moving specialist services out of hospitals and into communities can make services more accessible, responsive, and potentially more cost-effective.

3. Reducing health inequality

The 'inverse care law' is as relevant in Wales today as when it was proposed by Tudor-Hart in 1971, highlighting the link between inequalities in health and access to healthcare.

Welsh Government seeks to make care more equitable, reduce inequalities in healthcare access/ provision, with a focus on prevention of illness.

Our research activities, organised into eight work packages, will address the most pressing health needs within and across these themes.

PRIME welcomes Wales School of Social Prescribing Research

PRIME will also be the home of **Wales School of Social Prescribing Research (WSSPR)**, officially launched at the start of April 2020.

Led by Director, Professor Carolyn Wallace of the University of South Wales (USW) and co-chaired by Dr Sally Rees at the **Wales Council for Voluntary Action (WCVA)**, this virtual school based within PRIME Centre Wales aims to develop a **social prescribing evaluation methodology**.

It builds on the work previously completed by the Wales Social Prescribing Research Network (WSPRN). The network itself has won more than £700k in funding bids to date.

Professor Wallace comments:

"The rapidly growing enthusiasm for social prescribing and its potential to influence delivery of services in primary and community care have exceeded expectation, but the development of its evidence base and robust quality standards for evaluation have trailed,"

"There is variable evidence to suggest that social prescribing reduces the footfall to GP surgeries of between 15% to 28%.

The evidence varies so much because the impact of social prescribing depends on the type of model used, the link workers and their backgrounds, the locality, and the assets available within the community.

"Social prescribing is incredibly important. It helps people connect with their community and improve their well-being."

For further information, please visit: www.wsspr.wales

Themes for 2020-25



Aim:

To improve the health and well-being of people in Wales by producing world-leading, locally relevant high-impact research in primary and emergency care.

Themes & Workpackages:



Theme 1:

Value-based primary & emergency care

WP1. Infections & antimicrobial resistance
WP2. Emergency, unscheduled & prehospital care
WP3. Patient safety



Theme 2:

Seamless health & social care closer to home

WP4. Care closer to communities
WP5. Person-centred care
WP6. Supportive & palliative care



Theme 3:

Reducing health inequalities

WP7. Screening, prevention & early diagnosis
WP8. Oral health & primary dental care

Infrastructure wide activities:

Engagement, collaboration and co-production
Public and patient involvement & engagement
Knowledge translation, stakeholder engagement and impact
Communications, publicity, impact & knowledge transfer
Research portfolio development
Methodological development
Workforce development & capacity building



Canolfan
PRIME **Cymru**
Wales PRIME
Centre



www.primecentre.wales



info@primecentre.wales



[@primecentre](https://twitter.com/primecentre)